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## Estimating The Health And Economic Burden Of Cancer Among Those Diagnosed As Adolescents And Young Adults

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### Abstract

Adolescent and young adult cancer survivors—those who were ages 15–39 at their first cancer diagnosis—have important health limitations. These survivors are at risk for higher health care expenditures and lost productivity, compared to adults without a history of cancer. Using Medical Expenditure Panel Survey data, we present nationally representative estimates of the economic burden among people who were diagnosed with cancer in adolescence or young adulthood. Our findings demonstrate that surviving cancer at this age is associated with a substantial economic burden. Compared to adults without a history of cancer, adolescent and young adult cancer survivors had excess annual medical expenditures of \$3,170 per person and excess annual productivity losses of \$2,250 per person. Multifaceted prevention strategies, including education and sustained intervention programs to ensure access to lifelong risk-based follow-up care, may be

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effective ways to improve the economic outcomes associated with cancer survivorship in this population.

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An estimated 614,000 adolescent and young adult cancer survivors—people who had ever been diagnosed with cancer who were ages 15–39 at their first cancer diagnosis— were alive in the United States in 2012.<sup>1</sup> Although there have been improvements in cancer survival in the overall US population, adolescents and young adults have not experienced these improvements to the same degree as younger and older cancer patients have.<sup>2,3</sup>

All cancer survivors are at risk for developing chronic health conditions from the chemotherapy, radiation, and surgery they received during treatment. However, given the timing of their diagnosis and treatment and the possible interruption of normal developmental processes, adolescent and young adult cancer survivors also face unique medical, psychosocial, financial, and occupational challenges.<sup>2,4–7</sup>

Medical care in the years following cancer treatment is particularly important: Survivors need to be screened for lasting and late effects such as secondary cancers, infertility, and cardiac conditions, so that these conditions can be treated.<sup>8</sup> Furthermore, given developmental transitions during adolescence and young adulthood, a cancer diagnosis and its treatment could have substantial effects on educational attainment and labor-force participation among adolescents and young adults.<sup>7,9</sup>

Cancer survivorship has been shown to be associated with substantial medical expenditures and lost productivity—including employment disability (defined as being unable to work because of illness or injury), fewer hours worked, and more missed work days—among other populations of cancer survivors.<sup>10–17</sup> However, adolescents and young adults have been underrepresented in the cancer survivorship literature. As a result, substantial gaps remain in understanding the long-term consequences of surviving cancer in this age group.<sup>18</sup>

The Institute of Medicine convened a workshop in 2013 to address the gaps and challenges in caring for adolescent and young adult cancer survivors and to discuss potential strategies and actions to improve the quality of their care and outcomes.<sup>19</sup> Understanding the economic impact of cancer is an essential component of improving the outcomes among this population.

In this study we used nationally representative data to estimate direct medical costs and indirect morbidity costs among adolescent and young adult cancer survivors, compared to people without a history of cancer. We estimated direct medical costs by examining annual health care expenditures and indirect morbidity costs by examining lost productivity associated with employment disability, missed work days, and lost household productivity. Further investigations of the long-term economic consequences of surviving cancer among this population may be helpful in guiding the development of comprehensive intervention programs to improve the experience of adolescent and young adult cancer survivors and to decrease the economic burden of their survivorship on the United States as a whole.

## Study Data And Methods

### DATA AND SAMPLE SELECTION

To examine the health and economic burden of surviving cancer when it is first diagnosed in adolescence and young adulthood, we used a sample of people in this age group of survivors from the 2008–11 Medical Expenditure Panel Surveys (MEPS). MEPS is a nationally representative survey that is conducted annually among the US civilian noninstitutionalized population. MEPS uses an overlapping panel design and in-person interviews in which the respondent typically answers questions on behalf of all family members in the household. MEPS collects detailed information on sociodemographic characteristics, health care expenditures, and employment. More detailed information on the MEPS survey design and content is available elsewhere.<sup>20</sup>

We combined overlapping panels from the 2008–11 MEPS. The annual response rate ranged from 53.5 percent to 59.3 percent.

As noted above, we defined *adolescent and young adult cancer survivors* as people who were first diagnosed with cancer at ages 15–39. To identify these survivors, we used responses to a question asking whether a respondent had ever been told by a doctor or other health professional that he or she had cancer or a malignancy of any kind, and responses to a question asking about the age at diagnosis. Respondents with missing data on cancer history ( $n = 224$ ) or age at diagnosis ( $n = 308$ ) were excluded from the analysis.

Adult respondents with no reported history of cancer were used as the comparison group. We did not classify people with a cancer history of only nonmelanoma skin cancer as cancer survivors; instead, we included them in the comparison group.<sup>14,16</sup>

We identified 1,464 adolescent and young adult cancer survivors and 86,865 adults (ages eighteen and older) without a history of cancer in the pooled sample of 2008–11 MEPS data. MEPS survey weights were applied to account for the complex study design and to reflect the probability of selection and adjustments for non-response and poststratification. This process allowed us to provide nationally representative estimates. Analyses were conducted using the statistical software Stata, version 13.0.

### MEASURES

We examined a number of measures to assess the health burden among adolescent and young adult cancer survivors, including limitations in work, housework, or school; being completely unable to do activities (work at a job, do housework, or go to school); cognitive limitations; and limitations in physical functioning. We also assessed respondents' employment status and their reasons for not working, if they were not employed. We estimated the economic burden among survivors by examining excess direct medical costs and indirect morbidity costs, compared to adults without a history of cancer.

### DIRECT MEDICAL COSTS

Direct medical costs were estimated using all reported annual medical expenditures among adolescent and young adult cancer survivors and adults without a history of cancer. We

examined total annual medical expenditures and medical expenditures by source of payment (out of pocket, private health insurance, Medicare, Medicaid, and other sources) and service type (ambulatory care, inpatient care, prescription medications, and other services).

As is typical with medical expenditure data, our sample included many people with no expenditures and some people with very high expenditures. Therefore, we estimated annual expenditures using a two-part model.<sup>21</sup> The first part of the model used logistic regression to predict the probability of any medical expenditure. The second part predicted expenditures only for people with positive expenditures, using a generalized linear model with a gamma distribution and a log link.

Following the approach used in previous studies,<sup>16</sup> we controlled for age, sex, race or ethnicity, number of MEPS priority conditions as diagnosed by a health care professional, and US census region in each part of the model. All medical expenditures were adjusted to 2011 dollars using the Personal Health Care Expenditure Price Index.<sup>22</sup>

## INDIRECT MORBIDITY COSTS

We measured indirect morbidity costs by assessing employment disability, missed work days, and additional days spent in bed—that is, days in addition to those missed from work or school. Multivariable logistic regression modeling was used to estimate the adjusted percentage of people reporting employment disability while age, sex, race or ethnicity, number of MEPS priority conditions, education, and US census region were controlled for.

Productivity loss from employment disability was estimated by multiplying the adjusted percentage reporting employment disability by the median annual wage in 2011 (\$34,460) from the national occupational employment and wage estimates of the Bureau of Labor Statistics.<sup>23</sup> We used the median wage instead of actual wages because using actual wages would have resulted in a lower value for vulnerable subpopulations, which would raise equity concerns. Additionally, using actual wages would have implied that there was no value to the time lost for homemakers—that is, those who perform routine household services and do not have a job outside the home—and for retirees or people who were not in the labor force as a result of illness or injury.<sup>24</sup>

Missed work days were determined by assessing the number of days (a half-day or more) of work that employed people missed because of illness, injury, or mental or emotional problems. Lost productivity from additional bed days was calculated by determining the number of additional missed days in which at least a half-day was spent in bed because of illness or injury among all people. Negative binomial regression models were used to estimate the adjusted number of missed work days and additional bed days, with age, sex, race or ethnicity, number of MEPS priority conditions, education, and US census region controlled for.

Lost productivity from missed work days was calculated as the product of the adjusted average number of missed days and cost per day using the median hourly wage in 2011 (\$16.57) from the Bureau of Labor Statistics.<sup>23</sup> Because MEPS does not differentiate

between full and partial days missed, we assumed that each missed work day was six hours long.

Lost household productivity was calculated by multiplying the average number of additional bed days by the value of daily household productivity (\$41.88).<sup>25</sup> All productivity costs were adjusted to 2011 dollars using the Consumer Price Index.<sup>26</sup>

## SENSITIVITY ANALYSIS

We also conducted sensitivity analyses to examine the uncertainty of our estimates. Specifically, we examined the confidence intervals of our estimates and the sensitivity of the results to our exclusion criteria and to changes in wage and household productivity values. Additionally, to assess whether the economic burden was different for adolescent and young adult cancer survivors than for cancer survivors diagnosed at older ages, we conducted analyses of survivors who were at least age forty at the time of diagnosis. Details on the sensitivity analyses are available in the online Appendix.<sup>27</sup>

## LIMITATIONS

Although our study provides important data on the health and economic burden among adolescent and young adult cancer survivors, several limitations must be acknowledged. First, the study relied on household-reported data, and we did not have information on the stage of cancer at diagnosis, whether or not it recurred, or other clinical characteristics. Second, population-based surveys generally underestimate rare and short-survival, high-cost cancers.<sup>28,29</sup>

Third, because the cancer diagnosis question in MEPS refers to cancer or malignancy of any kind, it may include respondents with preinvasive disease. If it did, the likely result would be an underestimate of differences between adolescent and young adult cancer survivors and adults without a cancer history. Last, the sample size was not large enough for us to be able to examine the burden by cancer site.

## Study Results

### CHARACTERISTICS

Compared to adults without a history of cancer, adolescent and young adult cancer survivors were more likely to be older, female, non-Hispanic white, insured with Medicaid, and in fair or poor health; to have more MEPS priority conditions; and to have a lower income (Exhibit 1). In addition, the survivors were less likely to be employed and more likely to report limitations and being completely unable to do activities (Exhibit 2). Among people who were not working, survivors were more likely than others to report being unable to work because of illness or disability.

### ANNUAL DIRECT MEDICAL COSTS

Adolescent and young adult cancer survivors had higher annual per person medical expenditures (\$7,417) than adults without a history of cancer (\$4,247) (Exhibit 3). The largest sources of payment in both groups were private health insurance and Medicare. And

in both groups, ambulatory care and inpatient care accounted for the largest share of medical expenditures.

### ANNUAL INDIRECT MORBIDITY COSTS

Compared to adults without a history of cancer, adolescent and young adult cancer survivors were more likely to report employment disability, an increased number of missed work days as a result of illness or injury, and an increased number of additional days spent in bed as a result of poor health. Among survivors, total annual per capita lost productivity was \$4,564, compared to \$2,314 among adults without a history of cancer (Exhibit 4). Productivity loss resulting from employment disability accounted for the largest portion of total productivity loss in both groups.

### Discussion

This study indicates that the health and economic burden among adolescent and young adult cancer survivors is substantial, resulting in excess health care expenditures and lost productivity costs compared to adults without a history of cancer. Survivors were more likely not to be employed and to have limitations that were cognitive; physical; and related to work, housework, and school.

In 2008–11 the annual excess economic burden of cancer survivorship was \$5,420 per survivor. Excess medical expenditures accounted for 58.5 percent of the total excess burden (\$3,170 of the \$5,420) (Exhibit 3), with the remainder (\$2,250) from lost productivity (Exhibit 4). Combined, these results add to the growing body of literature that has examined the impact of a cancer diagnosis among adolescent and young adult cancer survivors, and they provide nationally representative estimates on the economic burden among this population.

Annual excess lost productivity was estimated to be \$2,250 per adolescent and young adult cancer survivor, which is substantially higher than lost productivity among older survivors (for lost productivity costs for older survivors, see the online Appendix).<sup>27</sup> The increased lost productivity observed among younger survivors may be due in part to the developmental transitions experienced by adolescents and young adults.

During adolescence and young adulthood, people with cancer may be completing their education or entering the workforce while they navigate diagnoses, health care decisions, and treatment.<sup>6</sup> A cancer diagnosis during this period may interrupt developmental transitions, which may have a significant influence on the survivor's potential earnings and future career development. Moreover, research has shown that adolescent and young adult survivors face challenges in returning to, or functioning in, school or work after a cancer diagnosis.<sup>7</sup>

In addition to affecting education and employment outcomes directly, a diagnosis of cancer in adolescence or young adulthood may limit access to important resources, such as employer-sponsored insurance.<sup>9</sup> We found that adolescent and young adult cancer survivors have greater medical care expenditures than adults without a history of cancer, even many

years after a cancer diagnosis (data not shown). This is consistent with the medical care required to treat the late effects of cancer treatment.

Given these increased medical expenditures, health insurance may be an important component of ensuring access to lifelong risk-based follow-up care and improving adherence to survivors' care plans. Cancer survivors younger than age thirty-five have been shown to have a difficult time obtaining health insurance.<sup>30</sup> This fact highlights the importance of monitoring health insurance needs among adolescent and young adult cancer survivors.

The Affordable Care Act is making health insurance more available in a number of ways: setting up health insurance Marketplaces where consumers may go to compare available insurance plans and enroll in a plan of their choice, providing the opportunity for states to expand coverage in their Medicaid programs, reforming insurance market rules (for example, prohibiting the denial of coverage for preexisting conditions), and requiring plans that offer coverage to children on their parents' plan to make the coverage available until the child reaches age twenty-six. Together, the increased opportunities for coverage under the act will help adolescent and young adult cancer survivors obtain health insurance for their medical care needs.

However, it is not clear whether insurance alone will ensure access to care among these survivors. Even with health insurance, they are more likely to avoid routine medical care because of its cost, compared to adults without a history of cancer.<sup>31</sup>

As this study shows, adolescent and young adult cancer survivors face higher out-of-pocket expenditures than do adults without a history of cancer (Exhibit 3). With increased out-of-pocket burdens and lower incomes, young survivors may need additional support as they transition out of care in the oncology setting—such as information on community health centers, financial assistance programs, care coordination, and care plans to improve their access to care following cancer treatment.<sup>31</sup>

To this end, stakeholders discussed key gaps and challenges in caring for adolescent and young adult patients with cancer at a recent Institute of Medicine meeting.<sup>19</sup> Attendees highlighted potential strategies and actions to guide stakeholders as they continue their work to improve the quality of care for this population.

Research assessing adolescent and young adult cancer survivors' needs for health and supportive care has shown the importance of age-appropriate resources and peer support.<sup>32</sup> Opportunities to meet other people with similar experiences may give these survivors a chance to address areas of concern to them, such as coping with uncertainty, forced dependence on others, sexuality and fertility, and educational and career plans.<sup>32</sup>

## Conclusion

Our results indicate that the economic burden among adolescent and young adult cancer survivors is substantial, resulting in excess health care expenditures and lost productivity costs compared to adults without a history of cancer. Efforts to reduce the health and



economic burden caused by cancer are important. Given the need to monitor these survivors for recurrence and the lasting and late effects of treatment, ensuring that they have access to health care is a matter of public health importance.

Even with adequate health insurance coverage, adolescent and young adult cancer survivors may have problems in obtaining medical care, including language barriers and lack of transportation, geographical access, and awareness of guidelines for the prevention of secondary cancers. Efforts to solve these problems could make the Affordable Care Act even more effective in increasing access to care among these survivors.

Identifying ways to reduce disruptions in education and at work as these survivors transition out of treatment is important for reducing the excess burden of cancer. This is of particular importance among the adolescent and young adult population, as survivors in this age group must find a way to complete their education and navigate the early stages of a career while coping with a cancer diagnosis and treatment. Efforts in this area could help maximize the employment opportunities and workplace productivity among younger cancer survivors.

## NOTES

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**Exhibit 1**

Characteristics Of Adolescent And Young Adult Cancer Survivors And Adults Without A History Of Cancer, 2008–11

	Cancer survivors (n=1,464)	Adults without cancer (n=86,865)
<b>TIME SINCE DIAGNOSIS (YEARS)</b>		
0–9	30.5%	__ <sup>a</sup>
10–19	27.7	__ <sup>a</sup>
20 or more	41.9	__ <sup>a</sup>
<b>AGE AT LAST INTERVIEW (YEARS) ****</b>		
18–29	11.0	23.7%
30–39	21.0	18.1
40–49	26.7	18.8
50–64	29.3	25.1
65 or older	12.0	14.3
<b>SEX ****</b>		
Male	22.2	49.0
Female	77.8	51.0
<b>RACE OR ETHNICITY ****</b>		
Non-Hispanic white	80.8	66.1
Non-Hispanic black	6.7	11.9
Hispanic	8.2	14.9
Non-Hispanic other	4.2	7.1
<b>EDUCATION</b>		
Less than high school graduate	15.5	16.9
High school graduate	29.6	29.5
Some college or more	54.7	53.2
<b>MARITAL STATUS</b>		
Married	53.1	52.8
Not married	46.9	47.2
<b>NUMBER OF MEPS PRIORITY CONDITIONS ****</b>		
0	30.4	46.7
1	23.7	22.6
2	18.3	14.1
3 or more	27.6	16.6

	Cancer survivors (n=1,464)	Adults without cancer (n=86,865)
<b>HEALTH INSURANCE****</b>		
Any private	66.0	67.8
Medicaid only	11.5	6.8
Medicare only	6.4	6.5
Medicare and Medicaid only	3.4	2.3
Other public only	0.4	0.3
Uninsured	12.3	16.3
<b>FAMILY INCOME****</b>		
Poor or near-poor (<125% of FPL)	21.4	16.7
Low or middle income (125–<400% of FPL)	41.6	44.0
High income (≥ 400% of FPL)	37.0	39.3
<b>HEALTH STATUS****</b>		
Excellent or very good	40.7	60.0
Good	31.2	27.8
Fair or poor	28.1	12.2
<b>CENSUS REGION**</b>		
Northeast	12.7	18.3
Midwest	24.2	21.5
South	37.9	36.2
West	24.4	23.2

**SOURCE** Authors' analysis of data from the 2008–11 Medical Expenditure Panel Surveys (MEPS).

**NOTES** Adolescent and young adult cancer survivors are those whose first diagnosis of cancer occurred at ages 15–39. Adults with no history of cancer (except for nonmelanoma skin cancer) are ages eighteen and older. Appropriate weighting was used to adjust for the complex sampling design. In addition to cancer, MEPS priority conditions are arthritis, asthma, diabetes, emphysema, coronary heart disease, hypertension, stroke, high cholesterol, angina, and heart attack. FPL is federal poverty level.

<sup>a</sup>Not applicable.

\*\*  
 $p < 0.05$

\*\*\*\*  
 $p < 0.001$

**Exhibit 2****Employment And Functional Limitations Of Adolescent And Young Adult Cancer Survivors And Adults Without A History Of Cancer, Adjusted Percentage, 2008–11**

	Cancer survivors	Adults without cancer
<b>EMPLOYMENT STATUS</b>		
Not employed****	33.4%	27.4%
Reason for not working		
Could not find work	20.7	21.8
Retired**	41.0	44.9
Unable to work because of illness or disability****	34.1	23.9
On maternity or paternity leave**	2.3	1.2
Going to school	7.6	9.2
Taking care of home or family	16.5	17.3
Other <sup>a</sup>	6.3	6.1
Never worked for pay	7.5	8.4
<b>FUNCTIONAL LIMITATIONS</b>		
Any limitation in work, housework, or school****	17.0	10.5
Completely unable to work at a job, do housework, or go to school****	11.9	6.7
Any cognitive limitation****	11.1	5.7
Any limitation in physical functioning****	20.8	14.6

**SOURCE** Authors' analysis of data from the 2008–11 Medical Expenditure Panel Surveys (MEPS).

**NOTES** Adolescent and young adult cancer survivors are those whose first diagnosis of cancer occurred at ages 15–39. Adults with no history of cancer (except for nonmelanoma skin cancer) are ages eighteen and older. Appropriate weighting was used to adjust for the complex sampling design. Adjusted percentages are from a logistic regression model with age, sex, race or ethnicity, education, number of MEPS priority conditions, and census region as covariates.

<sup>a</sup>“Other” includes on temporary layoff, wanted some time off, and waiting to start a new job.

\*\*  
 $p < 0.05$

\*\*\*\*  
 $p < 0.001$

**Exhibit 3****Adjusted Per Person Annual Medical Expenditures Among Adolescent And Young Adult Cancer Survivors And Adults Without A History Of Cancer, 2008–11**

	Cancer survivors		Adults without cancer	
	Adjusted expenditures	95% CI	Adjusted expenditures	95% CI
<b>SOURCE OF PAYMENT</b>				
All ****	\$7,417	(6,133, 8,700)	\$4,247	(4,142, 4,352)
Out of pocket **	765	(684, 846)	686	(670, 701)
Private insurance ****	3,083	(2,312, 3,854)	1,825	(1,758, 1,892)
Medicare *	1,246	(898, 1,594)	948	(901, 996)
Medicaid *	541	(361, 721)	380	(342, 418)
Other ****	876	(578, 1,174)	411	(387, 435)
<b>SERVICE TYPE</b>				
Ambulatory care <sup>a</sup> ****	2,409	(1,851, 2,968)	1,376	(1,335, 1,417)
Inpatient care **	1,605	(1,115, 2,096)	1,169	(1,116, 1,221)
Rx ****	1,466	(1,241, 1,691)	1,034	(970, 1,099)
Other <sup>b</sup> **	820	(694, 946)	686	(658, 714)

**SOURCE** Authors' analysis of data from the 2008–11 Medical Expenditure Panel Surveys (MEPS).

**NOTES** Adolescent and young adult cancer survivors are those whose first diagnosis of cancer occurred at ages 15–39. Adults with no history of cancer (except for nonmelanoma skin cancer) are ages eighteen and older. All monetary amounts were converted to 2011 dollars using the Personal Health Care Expenditure Price Index. Regressions controlled for age, sex, race or ethnicity, number of MEPS priority conditions, and census region using a two-part model. The sums of the components do not equal the totals because of nonlinearities. CI is confidence interval.

<sup>a</sup> Office-based provider visits and outpatient visits.

<sup>b</sup> Emergency department visits, home health visits, dental visits, vision expenses, and other medical expenditures.

\*  $p < 0.10$

\*\*  $p < 0.05$

\*\*\*\*  $p < 0.001$

**Exhibit 4**

Adjusted Per Person Annual Lost Productivity Among Adolescent And Young Adult Cancer Survivors And Adults Without A History Of Cancer, 2008–11

Type of lost productivity	Cancer survivors		Adults without cancer	
	Adjusted productivity loss	95% CI	Adjusted productivity loss	95% CI
Total per capita	\$4,564	(3,740, 5,387)	\$2,314	(2,196, 2,432)
Employment disability <sup>a</sup>	3,645	(3,051, 4,238)	1,828	(1,735, 1,921)
Missed work days (among employed people) <sup>b</sup>	500	(398, 603)	329	(316, 342)
Household productivity <sup>c</sup>	419	(291, 546)	157	(145, 169)

**SOURCE** Authors' analysis of data from the 2008–11 Medical Expenditure Panel Surveys (MEPS).

**NOTES** Adolescent and young adult cancer survivors are those whose first diagnosis of cancer occurred at ages 15–39. Adults with no history of cancer (except for nonmelanoma skin cancer) are ages eighteen and older. All monetary amounts are in 2011 dollars. Regressions controlled for age, sex, race or ethnicity, number of MEPS priority conditions, education, and census region. All differences are significant ( $p < 0.001$ ). CI is confidence interval.

<sup>a</sup>Median annual wage in 2011 (\$34,460) multiplied by the adjusted percentage unable to work because of illness or injury.

<sup>b</sup>Median national daily wage in 2011 (\$16.57 per hour multiplied by 6 hours, or \$99.42 per day) multiplied by the adjusted average number of days lost from work.

<sup>c</sup>Value of daily home productivity (\$41.88) multiplied by the adjusted number of additional days spent in bed (that is, days in addition to those missed from work or school).